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Development of a Minimum Data Set for a Needs Assessment Tool for Families of Children with Hearing Loss in the Transition to Early Intervention

An eDelphi study

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Background

- Assessing and meeting the unique needs of families of children with hearing loss is key to ensuring that families can make informed decisions (Minchom, Shepherd, White, Hill, & Lund, 2003).
- Decisions for communication approaches, assistive technologies, mode of service delivery, and relocating their home.
- Families need to make these important decisions in a timely manner while they might be under stress (Quittner et al. 2010).
- Therefore, a wealth of information and support is required.

Background

- Each family is unique depending on the families’ characteristics, capacities, beliefs, and situations (Magi & Allander, 1981).
- In the first phase of this project, we explored the needs of families of children with hearing loss during the period from diagnosis of hearing loss to enrolment in early intervention.
- Consistent with the literature (Fitzpatrick, Angus, Durieux-Smith, Graham, & Coyle, 2008; Most & Zaidman-Zait, 2003; van der Spuy & Pottas, 2008), our study found that families needed **individualised** informational, professional, and peer support that meets their specific needs.

Background

Behaviour Change Wheel

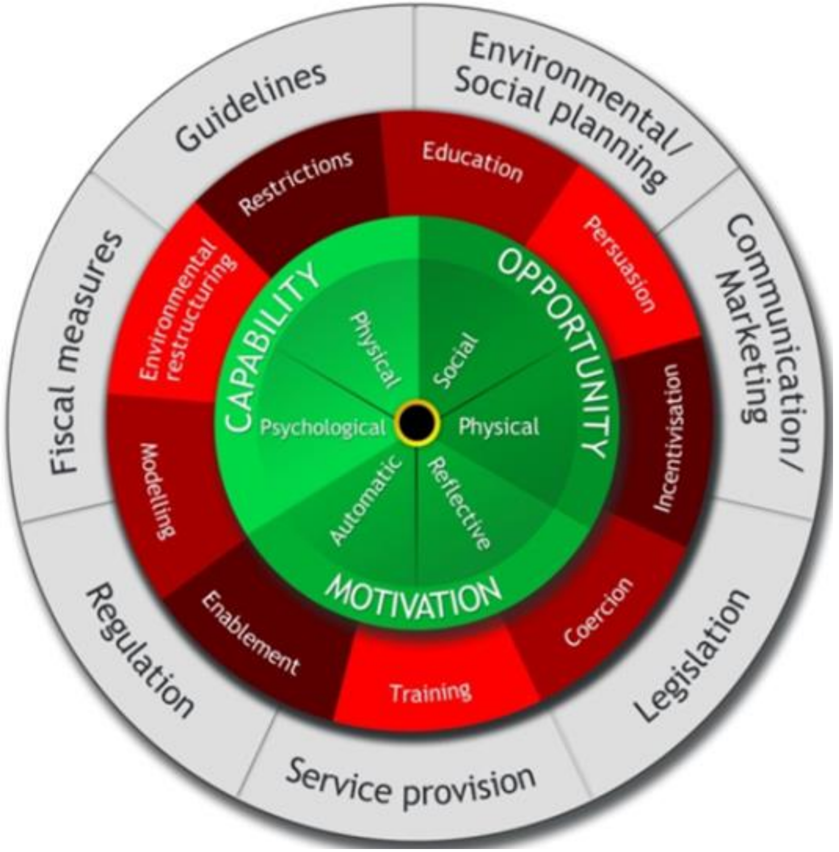
Problem:

The provision of individualised information and support to families of children with hearing loss in the transition to early intervention.

Barrier:

Limitation in resources for needs assessment.

- Family Needs Survey (FNS) (Bailey Jr & Simeonsson, 1988)
- Modified FNS for preschool children with hearing loss (Dalzell, Nelson, Haigh, Williams, & Monti, 2007)
- Family Support Needs Instrument–Children with Hearing Loss (FSNI-HL) for pre-adolescents and adolescents with hearing loss (Jamieson, Zaidman-Zait &Poon, 2011)



Aims

To identify the main items in terms of a Minimum Data Set (MDS) to be included in a Needs Assessment Tool so that the tool is reflective of the needs of families of children with hearing loss transitioning into early intervention.

Methods

- A two-round modified electronic Delphi (eDelphi) technique

- Participants (N=100):

1. Researchers with expertise in working with children with hearing loss (panelists)

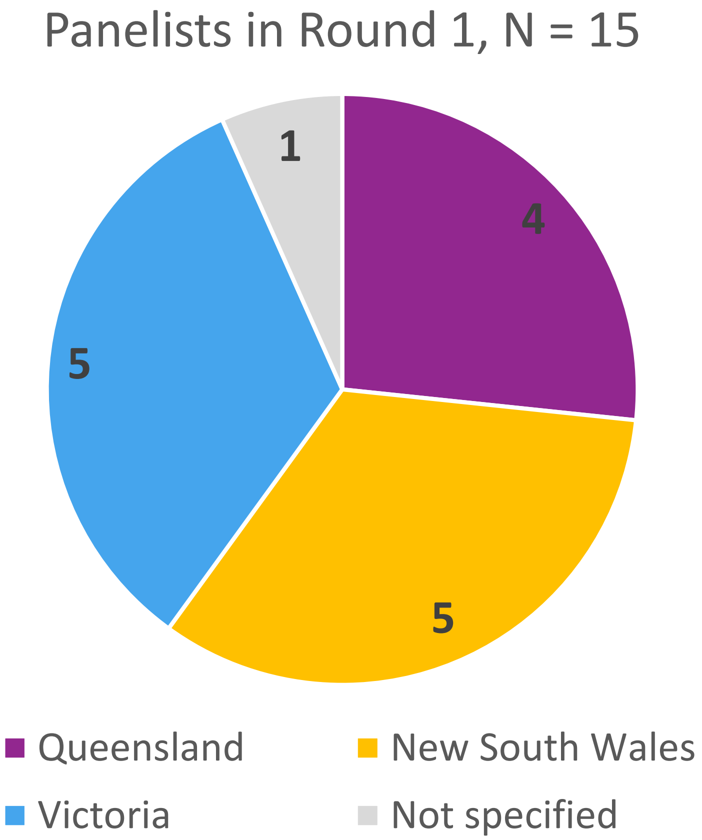
   (n = 15 in Round 1 and n = 9 of them in Round 2)

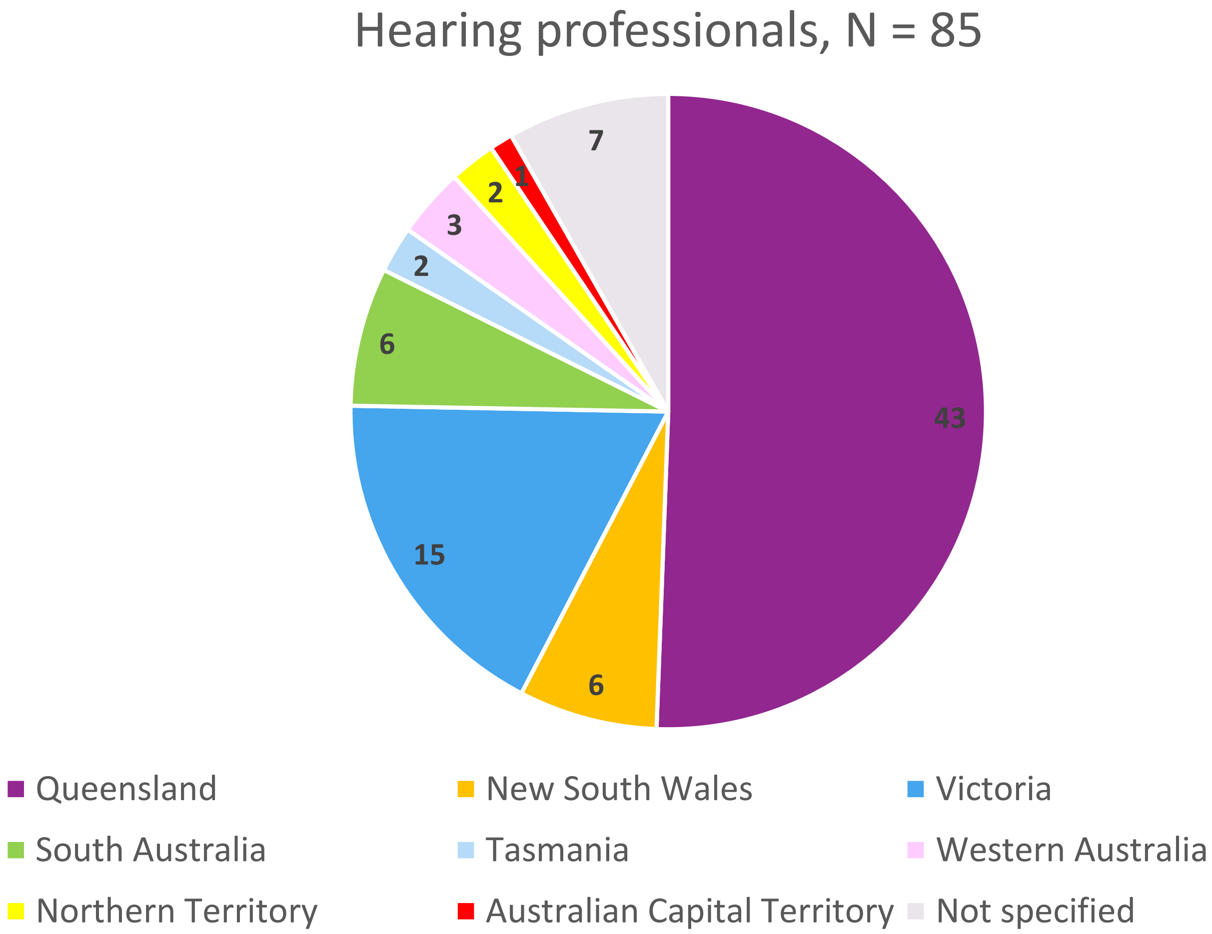
2. Professionals with experience in working with children with hearing loss, including clinicians and Teachers of the Deaf (n = 85)

Methods: Participants

Background	Panelists Round 1 N = 15(%)	Hearing professionals N = 85(%)
Audiologist	6 (40)	17 (20)
Teacher of the Deaf	1 (6.67)	24 (28.23)
Speech Pathologist	3 (20)	14 (16.47)
Both Audiologist and Speech Pathologist	0	3 (3.53)
ENT	4 (26.67)	3 (3.53)
Psychologist	1 (6.67)	3 (3.53)
Paediatrician	0	6 (7.06)
Social Worker	0	5 (5.88)
Occupational Therapist	0	1 (1.18)
Educational Interpreter	0	1 (1.18)
Clinical Geneticist	0	1 (1.18)
Not Specified	0	7 (8.23)

Methods: Participants

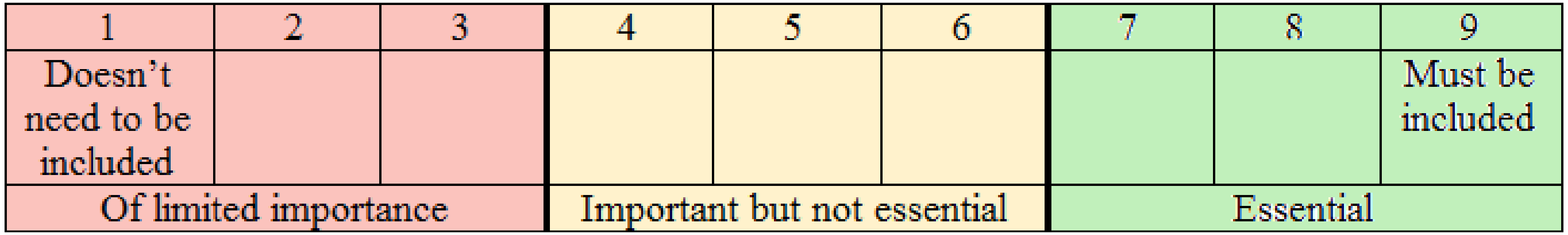




Methods: Materials

- Online questionnaire for participants to indicate their level of agreement regarding the inclusion of each potential item in the MDS

- Modified version of the Grading of Recommendations Assessment, Development, and Evaluation (GRADE) working group



1	2	3	4	5	6	7	8	9
Doesn't need to be included								Must be included
Of limited importance			Important but not essential			Essential		

- An open-ended question: Are there any items you would like to include in the list above?

Process and Results

Developing the survey for Round 1

42 possible items derived by research team based on a literature review and first phase (interview families and support professionals).

Round 1

15 panelists (researchers) rated the 42 items on a 9 point scale.

Panelists were encouraged to suggest more items.

Round 1 analysis

21 items reached consensus.

3 new items and 2 modifications suggested.

Developing the survey for hearing professionals

45 items from Round 1 included in the survey.

Hearing professionals' survey analysis

85 professionals completed the survey.

16 out of 21 items that reached consensus by panelists were identified as essential by hearing professionals too (main items).

Round 2

Panelists provided with: (1) a list of items that were modified according to the suggestions from Round 1 and professionals' survey, (2) a copy of their own responses, (3) the overall group ratings from Round 1, and (4) hearing professionals' ratings.

Panelists were asked to re-rate 29 items where there was less than 70% agreement in Round 1 as well as the items that were new, rephrased, or modified.

Round 2 analysis

9 panelists completed the survey.

16 items reached 70% or more agreement (main items).

8 items reached 50-69% agreement (optional items).

5 items reached less than 50% agreement (discarded).

Minimum Data Set for Needs Assessment in Families of Children with Hearing Loss Transitioning to Early Intervention

Main Items	
Informational Support (13 elements)	
1	Nature of hearing loss (e.g., permanent/temporary and congenital/acquired/genetic hearing loss)
2	Types of hearing loss (Sensorineural hearing loss, Conductive hearing loss, and mixed hearing loss)
3	Impacts of hearing loss
4	How to interpret diagnosis and hearing test results
5	Early intervention options (evidence-based information)
6	Hearing aids
7	Cochlear implants
8	What will happen if my child does not receive early intervention
9	Local early intervention services and educational options
10	Early intervention services over the internet (telepractice)
11	Sign language (e.g., benefits, evidence-based information, Auslan Language Models)
12	What happens next in the assessment, support, and early intervention pathway
13	The needs and potential of my child with hearing loss

Minimum Data Set for Needs Assessment in Families of Children with Hearing Loss Transitioning to Early Intervention

Main Items	
Professionals Support (5 elements)	
14	Information about the roles of different professionals (e.g., medical professionals, speech pathologists, Teachers of the Deaf, Advisory Visiting Teachers) in the team
15	Information about the best person to contact to ask questions
16	Support to cope with feelings about my child’s hearing loss (emotional support and reassurance)
17	Support to make decisions
18	Information about available interpreter services

Peer Support (1 elements)	
19	Support groups of other parents of children with hearing loss (e.g., playgroups)

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Minimum Data Set for Needs Assessment in Families of Children with Hearing Loss Transitioning to Early Intervention

Main Items	
Skills and Knowledge (7 elements)	
20	How to communicate with my child with hearing loss
21	How to bond with my child with hearing loss
22	How to optimise my child's social-emotional development
23	How to explain my child's hearing loss to others (e.g., siblings, neighbours)
24	How to optimise my child's communication development
25	How to build confidence in parenting my child with hearing loss
26	How to play with my child

Minimum Data Set for Needs Assessment in Families of Children with Hearing Loss Transitioning to Early Intervention

Main Items	
Financial Support (3 elements)	
27	Available funding for my child (e.g., National Disability Insurance Scheme)
28	Available funding for my family
29	Available funding for transportation to appointments

Methods of Information Provision (3 elements)	
30	Preferred mode for receiving information (e.g., paper-based, phone, email, in-person to discuss the information)
31	Written information in another language
32	Who else in your child's life you would like to receive information (e.g., child's grandparents, family friends)

Minimum Data Set for Needs Assessment in Families of Children with Hearing Loss Transitioning to Early Intervention

Optional Items	
1	Causes of hearing loss
2	Terminology related to hearing loss
3	Child’s prognosis for auditory skill and communication development
4	Other assistive technologies
5	Other special needs or disabilities my child may have
6	How hearing loss may impact my child at school
7	How to connect with other parents of children with hearing loss on social media
8	How to learn sign language

Clinical implications

Shared decision-making in clinical practice

Support families' in prioritising their needs

Support professionals in the provision of individualised information

Improve family-centred care

MDS for a Needs Assessment Tool for families of children with hearing loss

Promotes family/ professional collaboration

Research and education

Policymakers can collect uniform and essential data

Improves families' satisfaction

Conclusion

- Consensus was reached on 32 items to be included in the MDS across 6 categories, including:
    - informational support
    - professional support
    - peer support
    - skills and knowledge
    - financial support
    - methods of information provision.
- The proposed MDS could support hearing professionals to identify families' needs in order to provide individualised information and services.

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Thank you

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